

HR 1138 IH

108th CONGRESS

1st Session

H. R. 1138

To amend the Public Health Service Act to provide for Alzheimer's disease research and demonstration grants.

IN THE HOUSE OF REPRESENTATIVES**March 6, 2003**

Mr. MARKEY (for himself and Mr. SMITH of New Jersey) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to provide for Alzheimer's disease research and demonstration grants.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the 'Alzheimer's Disease Research, Prevention, and Care Act of 2003'.

SEC. 2. FINDINGS.

Congress makes the following findings:

- (1) Alzheimer's disease is a disorder that destroys cells in the brain. The disease is the leading cause of dementia, a condition that involves gradual memory loss, decline in the ability to perform routine tasks, disorientation, difficulty in learning, loss of language skills, impairment of judgment, and personality changes. As the disease progresses, people with Alzheimer's disease become unable to care for themselves. The loss of brain cells eventually leads to the failure of other systems in the body.
- (2) In the United States, 4,000,000 people have Alzheimer's disease and 19,000,000 people say that they have a family member with the disease. By 2050, 14,000,000 people in the United States will have Alzheimer's disease unless science finds a way to prevent or cure the disease.
- (3) One in 10 people over the age of 65, and nearly half of those over the age of 85 have

Alzheimer's disease. Younger people also get the disease.

(4) The Alzheimer's disease process may begin in the brain as many as 20 years before the symptoms of Alzheimer's disease appear. A person will live an average of 8 years and as many as 20 once the symptoms of Alzheimer's disease appear.

(5) The average lifetime cost of Alzheimer's disease, per person, is \$174,000.

(6) In 2000, medicare alone spent \$31,900,000,000 for the care of individuals with Alzheimer's disease and this amount is projected to increase to \$49,300,000,000 in 2010.

(7) Forty-nine percent of medicare beneficiaries who have Alzheimer's disease also receive medicaid. Of the total population dually eligible for medicare and medicaid, 22 percent have Alzheimer's disease.

(8) Seven in 10 people with Alzheimer's disease live at home. While almost 75 percent of home care is provided by family and friends, the average annual cost of paid care for people with Alzheimer's disease at home is \$19,000.

(9) Nearly 60 percent of all nursing home residents have Alzheimer's disease or another dementia. The average annual cost of Alzheimer's disease nursing home care is nearly \$64,000. Medicaid pays nearly half of the total nursing home bill and helps 2 out of 3 residents pay for their care. Medicaid expenditures for nursing home care for people with Alzheimer's disease are estimated to increase from \$18,200,000,000 in 2000 to \$33,000,000,000 in 2010.

(10) In fiscal year 2002, the Federal Government spent an estimated \$598,900,000 on Alzheimer's disease research. If our Nation achieves its research goals (preventing the onset of Alzheimer's disease in those at risk and treating and delaying progression of the disease in those who have symptoms), the projected number of cases of Alzheimer's disease can be reduced by more than one-third by the middle of the century and the number of baby boomers with moderate to severe Alzheimer's disease can be reduced by 60 percent.

(11) A study commissioned by the United Hospital Fund estimated that the annual value of this informal care system is \$257,000,000,000. Family caregiving comes at enormous physical, emotional, and financial sacrifice, putting the whole system at risk.

(12) One in 8 Alzheimer's disease caregivers becomes ill or injured as a direct result of caregiving. One in 3 uses medication for problems related to caregiving. Older caregivers are 3 times more likely to become clinically depressed than others in their age group.

(13) Elderly spouses strained by caregiving are 63 percent more likely to die during a given 4-year period than other spouses their age.

(14) Three of 4 caregivers are women. One in 3 has children or grandchildren under the age of 18 living at home. Caregiving leaves them less time for other family members and they are much more likely to report family conflicts because of their caregiving role.

(15) Most Alzheimer's disease caregivers work outside the home before beginning their caregiving careers, but caregiving forces them to miss work, cut back to part-time, take less

demanding jobs, choose early retirement, or give up work altogether. As a result, in 2002, Alzheimer's disease cost American business an estimated \$36,500,000,000 in lost productivity, as well as an additional \$24,600,000,000 in business contributions to the total cost of care.

SEC. 3. PRIORITY TO ALZHEIMER'S DISEASE RESEARCH.

Section 443 of the Public Health Service Act (42 U.S.C. 285e) is amended--

(1) by striking 'The general' and inserting '(a) IN GENERAL- The general'; and

(2) by adding at the end the following:

'(b) PRIORITIES- The Director of the Institute shall, in expending amounts appropriated under this subpart, give priority to conducting and supporting Alzheimer's disease research.'.

SEC. 4. ALZHEIMER'S DISEASE PREVENTION INITIATIVE.

Section 444 of the Public Health Service Act (42 U.S.C. 285e-1) is amended--

(1) in subsection (d), by inserting 'and training' after 'conduct research'; and

(2) by adding at the end the following:

'(e) The Director of the National Institutes of Health shall, in collaboration with the Director of the Institute, the directors of other relevant institutes, and with volunteer organizations and other stakeholders, undertake an Alzheimer's Disease Prevention Initiative to--

'(1) accelerate the discovery of new risk and protective factors for Alzheimer's disease;

'(2) rapidly identify candidate diagnostics, therapies, or preventive interventions or agents for clinical investigations and trials relating to Alzheimer's disease;

'(3) support or undertake such investigations and trials; and

'(4) implement effective prevention and treatment strategies, including strategies to improve patient care and alleviate caregiver burdens relating to Alzheimer's disease.'.

SEC. 5. ALZHEIMER'S DISEASE CLINICAL RESEARCH.

(a) CLINICAL RESEARCH- Section 445F of the Public Health Service Act (42 U.S.C. 285e-8) is amended to read as follows:

'SEC. 445F. ALZHEIMER'S DISEASE CLINICAL RESEARCH.

'(a) IN GENERAL- The Director of the Institute, pursuant to subsections (d) and (e) of section 444, shall conduct and support cooperative clinical research regarding Alzheimer's disease. Such research shall include--

- `(1) investigating therapies, interventions, and agents to detect, treat, slow the progression of, or prevent Alzheimer's disease;
- `(2) enhancing the national infrastructure for the conduct of clinical trials;
- `(3) developing and testing novel approaches to the design and analysis of such trials;
- `(4) facilitating the enrollment of patients for such trials, including patients from diverse populations;
- `(5) developing improved diagnostics and means of patient assessment for Alzheimer's disease; and
- `(6) as determined appropriate by the Director of the Institute, the Alzheimer's Disease Centers and Alzheimer's Disease Research Centers established under section 445.

`(b) EARLY DIAGNOSIS AND DETECTION RESEARCH-

`(1) IN GENERAL- The Director of the Institute, in consultation with the directors of other relevant institutes and centers of the National Institutes of Health, shall conduct, or make grants for the conduct of, research related to the early detection and diagnosis of Alzheimer's disease and of mild cognitive impairment or other potential precursors to Alzheimer's disease.

`(2) EVALUATION- The research described in paragraph (1) may include the evaluation of diagnostic tests and imaging techniques.

`(c) VASCULAR DISEASE- The Director of the Institute, in consultation with the directors of other relevant institutes and centers of the National Institutes of Health, shall, conduct or make grants for the conduct of, research related to the relationship of vascular disease and Alzheimer's disease, including clinical trials to determine whether drugs developed to prevent cerebrovascular disease can prevent the onset or progression of Alzheimer's disease.

`(d) NATIONAL ALZHEIMER'S COORDINATING CENTER- The Director of the Institute may establish a National Alzheimer's Coordinating Center to facilitate collaborative research among the Alzheimer's Disease Centers and Alzheimer's Disease Research Centers established under section 445.'.

(b) ALZHEIMER'S DISEASE CENTERS- Section 445(a)(1) of the Public Health Service Act (42 U.S.C. 285e-2(a)(1)) is amended by inserting ', and outcome measures and disease management' after 'treatment methods'.

SEC. 6. RESEARCH ON ALZHEIMER'S DISEASE CAREGIVING.

Section 445C of the Public Health Service Act (42 U.S.C. 285e-5) is amended--

(1) by striking 'SEC. 445C. (a)' and inserting the following:

`SEC. 445C. RESEARCH ON ALZHEIMER'S DISEASE SERVICES AND

CAREGIVING.

`(a) SERVICES RESEARCH-';

(2) by striking subsections (b), (c), and (e);

(3) by inserting after subsection (a) the following:

`(b) INTERVENTIONS RESEARCH- The Director shall, in collaboration with the directors of the other relevant institutes and centers of the National Institutes of Health, conduct, or make grants for the conduct of, clinical, social, and behavioral research related to interventions designed to help caregivers of patients with Alzheimer's disease and related disorders and improve patient outcomes.'; and

(4) in subsection (d) by striking `(d) the Director' and inserting `(c) MODEL CURRICULA AND TECHNIQUES- The Director'.

SEC. 7. AUTHORIZATION OF APPROPRIATIONS.

(a) IN GENERAL- Section 445J of the Public Health Service Act (42 U.S.C. 285e-11) is amended by striking `\$500,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 and 1996.' and inserting `\$1,100,000,000 for fiscal year 2004, \$1,200,000,000 for fiscal year 2005, \$1,300,000,000 for fiscal year 2006, \$1,400,000,000 for fiscal year 2007, and \$1,500,000,000 for fiscal year 2008.'.

(b) AGING PROCESS REGARDING WOMEN- Section 445H(b) of the Public Health Service Act (42 U.S.C. 285e-10(b)) is amended by striking `2003' and inserting `2008'.

(c) CLINICAL RESEARCH AND TRAINING AWARDS- Section 445I(d) of the Public Health Service Act (42 U.S.C. 285e-10a(d)) is amended by striking `2005' and inserting `2008'.

SEC. 8. ALZHEIMER'S DISEASE DEMONSTRATION GRANTS.

Section 398B(e) of the Public Health Service Act (42 U.S.C. 280c-5(e)) is amended--

(1) by striking `and such' and inserting `such'; and

(2) by inserting before the period `, \$20,000,000 for fiscal year 2004, and such sums as may be necessary for each of the fiscal years 2005 through 2008'.

END